In the Public Eye

Beyond Our Borders

The effects of HIV infection and AIDS on children in Africa

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Two months ago, I was in rural Uganda with a team of local researchers. Mud houses with grass roofs were connected by a maze of footpaths, and roads were few and far between. We were there to interview people in homes where children were affected by AIDS. Some of the children were living with an HIV-positive parent. Others were already orphans and had been taken in by a relative. It struck me, as we advanced awkwardly by van, how frequently we stopped at eligible homes to dispatch an interviewer. You could throw a stone from one household confronted with AIDS, and it would land in the neat garden plot of the next.

This disease closes in on children from all sides in the hard-hit regions of East and Southern Africa. Children nurse their parents during prolonged illness and watch them suffer and die. Some even watch their guardians succumb to AIDS. They lose sisters and brothers, uncles and aunts, teachers and leaders. At the very least, they grow up sharing their meals with orphaned cousins.

The US Bureau of the Census estimates that, by the end of 2000, 15.6 million chil-

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An orphaned child in Uganda who is now cared for by his grandmother

dren around the world had lost a mother or both parents to AIDS. By 2010, at least 44 million children will have lost a mother, father, or both parents to AIDS. Even these daunting figures exclude older orphans aged 15 years and older, children orphaned by war and other causes, orphans on the streets and in institutions, and children whose parents are ill with opportunistic infections of AIDS.

Perhaps the unluckiest children of all are those infected from birth or in infancy. True, we can take heart in our slowly improving ability to reduce the transmission of HIV from mother to child. But already 1.5 million children in Africa are living with AIDS. And until HIV-positive mothers are kept alive, their virus-free children are sentenced to orphanhood and its attendant vulnerabilities.

WHO TAKES CARE OF ORPHANS?

Throughout East and Southern Africa, families are the first and most important source of love and care for children orphaned by AIDS. Most of the children are taken in by aunts, uncles, and grandparents—a response built on a strong and long-standing tradition of extended family networks and informal fostering.

As the epidemic progresses, however, the strongest guardians fall sick themselves or become overwhelmed with dependents. Orphans are left with increasingly vulnerable guardians—elderly grandparents, young siblings, and relatives who are themselves infected with HIV—or none at all. The growing number of street children and child-headed households is a sign that family safety nets are stretched to their limit.

In many places, community groups and religious organizations make up for this gap through spontaneous and determined outreach to the "epidemic" of orphans. Volunteers, predominantly women, visit the sick and raise funds to feed orphans and send them to school. With momentum and good leadership, these groups become community mobilizers and advocates. Some expand to offer savings-and-credit schemes for affected families, formal and vocational training for orphans, and a range of other services (see box 1).

Inevitably, orphans fall through the cracks. Children from migrant families, for example, may not know their relatives. There is little institutional care, formal foster care, or adoption. Slowly, governments are responding. Malawi was one of the first countries to develop a policy framework for orphans. Other governments, like those of Botswana, Uganda, South Africa, Zambia, and Zimbabwe, have followed suit, with policies and programs to support orphans and to protect their rights. Still, existing government welfare systems are inadequate to provide for a generation of orphans numbering in the millions.

Box 1
Caring for AIDS orphans in Africa

- A "succession planning" program in Uganda strives to reach children early by assisting HIV-positive parents to plan for their children's future. Parents are encouraged to appoint guardians, to talk openly with their children about the future and about HIV infection and AIDS, to write wills, and to create "memory books" (akin to scrapbooks) so as to leave children with a sense of family history and cultural heritage
- Efforts to increase access to school for AIDS-affected children have taken different forms. Some communities raise funds for education and rally teachers to keep an eye on vulnerable children. The governments of Uganda and other countries have abolished primary school fees. In Zambia, experiments are underway with radio-based education and volunteer-driven community-based schools
- Communities respond—sometimes with assistance from external organizations—by forming village orphan "committees" to identify and visit vulnerable children, identify their needs, and raise funds to meet those needs. In Zimbabwe, a unique fostering program on a commercial farm provides long-term support to orphans from migrant families who have lost touch with their extended families. Urban reunification programs seek to reunite street children with distant relatives

HOW DOES AIDS AFFECT THE LIVES OF CHILDREN IN AFRICA?

Serious adult illness puts households under enormous financial stress. Parents incur medical expenses and are less able to farm and work for wages. Children face diminishing resources for food, school, health care, and clothes. Bereaved survivors struggle to pay for funeral expenses. And widows and orphans stand to lose their land, homes, and possessions in areas where their rights to property and inheritance are neglected.

Many AIDS-affected households lack adequate food, and child nutrition suffers as a result. Routine immunizations and other preventive care can be overlooked by sick parents or new guardians, leaving AIDS-affected children prone to illness. In fostering households, poverty deepens with each orphan taken in. Thus, overwhelmed guardians may choose to feed their own children first, leaving orphans hungry and malnourished.

Young people, especially girls and older

Box 2
Key publications on HIV infection and AIDS in children

- Foster G, Williamson J. A review of current literature on the impact of HIV/AIDS on children in sub-Saharan Africa. *AIDS* 2000;14:S275-S284.
- Hunter S, Williamson J. *Children on the Brink: Strategies to Support Children Isolated by HIV/AIDS. Executive Summary: Updated Estimates and Recommendations for Intervention.* Washington, DC: USAID (US Agency for International Development); 2000. www.synergyaids.com/children.htm.
- Gilborn LZ, Nyonyintono R, Kabumbuli R, Jagwe-Wadda G. Making a Difference for Children Affected by AIDS: Baseline Findings from Operations Research in Uganda. *Horizons Research Report* Washington, DC: Horizons Program; 2001. www.popcouncil.org/pdfs/horizons/orphansbsln.pdf.
- Monk N. Underestimating the magnitude of a mature crisis: dynamics of orphaning and fostering in rural Uganda. In: *Orphan Alert: Children Orphaned by AIDS.* Lutry, Switzerland: Association François-Xavier Bagnoud; 2000:7-12. orphans.fxb.org/inform/reports.html.
- Ntozi J. Effect of AIDS on children: the problem of orphans in Uganda. *Health Transit Rev* 1997;7(suppl):23-40.
- UNAIDS and WHO. *AIDS Epidemic Update.* Geneva: Joint United Nations Programme on HIV/AIDS and World Health Organization; December 2000. www.unaids.org/wac/2000/wadoo/files/WAD_epidemic_report.htm.
- UNICEF. *Children Orphaned by AIDS: Front-Line Responses From Eastern and Southern Africa.* New York, NY: UNICEF; December 1999.

children, take on expanded, adult roles when their parents are sick. They help with household chores, farming, caring for younger children, and nursing sick adults. These responsibilities foreshorten normal childhood and interfere with schooling. For children taken in by weak guardians, this burden continues into orphanhood.

Poorer access to school puts orphans at an educational and economic disadvantage but also represents a threat to their psychological well-being. Being in school, having contact with a teacher and other children, and having the proper school supplies are crucial to a child's sense of well-being and belonging. Having to drop out of school is a crushing blow.

Indeed, one of the most important effects of AIDS on children is emotional. Children witness the prolonged suffering and death of parents and other loved ones. Some shift "foster" homes several times as even their guardians die. Others lose contact with siblings shunted to different households. They lose opportunities and fear that they, too, are infected with HIV. And because of the silence surrounding HIV and AIDS, they worry alone about their future. In Uganda, for instance, we found that most children wanted their parents to talk to them about being HIV-positive and about what will happen when the parents die but that parents fear and avoid doing so. The strain of parental illness and death trigger anxiety, fear, sadness, withdrawal, and depression. Many children in Africa are growing up in the relative absence of adult love, protection, and guidance. We have yet to fully grasp what this means for the future economic and social stability of their societies.

Stigma and discrimination also contribute to the emotional toll of AIDS. Neighbors keep a distance for fear of infection and gossip about infected parents. Peers commonly tease and isolate the children. Teachers may turn children away for lack of school supplies, with no consideration of their family circumstances. And guardians who experience orphans as a burden may shun them, neglect them, or worse.

Finally, as orphaned youth reach adolescence, they join the ranks of the highest risk group for HIV infection in Africa. Youth aged 15 to 24 years now account for 50% of new cases of HIV infection in high-prevalence areas, with girls becoming infected at younger ages. Orphaned youth tend to begin sexual activity earlier than their peers and are especially vulnerable to coercive and transactional sex, unwanted pregnancy, and infection with HIV and other sexually transmitted infections. Orphaned girls can be pushed into early marriage to alleviate the burden on relatives to provide for them. Lacking adult protection, girls, street children, and those in child-headed households are particularly vulnerable to exploitation.

HOW CAN WE RESPOND?

A number of program principles and models have blossomed from the cumulative experience of African and international groups working with children affected by AIDS. The consensus is that the first priority is to strengthen family and community capacity to support orphans. Institutional care has a place where abandoned and desperate children are concerned, but it is costly and ineffective at ensuring a nurturing environment. Programs should reach all orphans and vulnerable children rather than singling out those affected by AIDS. We are learning to pay special attention to the vulnerabilities of girl orphans and to the needs of older children for skills to support and protect themselves. We have also learned the importance of reaching children early—as soon as their parents fall sick—rather than waiting until they become orphans.

In all that we do, we must be guided by the fundamental rights of children to family, community, and culture, to education and play, to health and safety, and—very important—to a voice in the issues that affect them. The immense challenge that remains is to deliver protection and services to all children infected and affected by AIDS and to do so for decades to come. Finally, however, the best thing we can do for children is to keep their parents alive, not only with access to sound medical care, but through a relentless effort toward the ultimate goal: prevention.

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